Case Study of an Infant with a Critical Illness and the Benefits of Occupational Therapy Intervention Throughout Hospitalization

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Abstract

Critically ill infants experience prolonged immobility, sedation, feeding intolerance, and often ventilator dependence as a result of medical complexity that results in lengthy hospitalization. The complex, fragile and vulnerable population of critically ill infants is at greatest risk for developmental sequelae. Although occupational therapy has played a crucial role in the therapeutic outcome of critically ill infants, current literature documenting best practice and treatment protocols is limited. A single subject case study design was used with a critically ill infant in a neonatal intensive care unit to characterize the impact of occupational therapy intervention throughout hospitalization including acute, subacute, and transition to home stages. This case study defines occupational therapy standard of care and model of practice in the neonatal intensive care setting. It also serves as a basis for future studies establishing treatment protocols to guide the occupational therapy profession in this specialized neonatal intensive care environment.

Introduction

Occupational therapy's domain and focus of practice is derived from the profession's interest in human beings' ability to engage in everyday life occupations or activities that are meaningful and purposeful (American Occupational Therapy Association, 2002). Infants in a Neonatal Intensive Care Unit (NICU) engage in daily occupations or activities that are critical to the developmental outcomes of infants. Occupations of an infant include feeding, socially interacting, exploratory play (visual, auditory, oral, tactile, proprioceptive, and vestibular), procuring (care soliciting), and life sustaining work (i.e. breathing). Vergara and Bigsby (2004) define infant occupations as "appropriate tasks and activities that are valued in either the family's culture or the NICU culture within which an infant is expected to participate" (p. 3). An infant's

medical complexity, ability to transition among states of arousal, ability to demonstrate appropriate behavioral cues, and the NICU environment effects an infant's participation in occupations and caregiver's participation in occupations.

The medical complexity of the infant in the NICU affects his/her physiological stability, motor capabilities, arousal, and ability to interact with the environment resulting in a limitation in occupational engagement. The occupations of the caregivers of infants in a NICU are also greatly impacted by the infants' medical status and uncertain outcome. The role of a caregiver is disrupted by an infant's hospitalization, and caregivers are unable to engage in occupations consistent with the typical parental role (i.e. feeding, nurturing, holding) (Anzalone, 1994). An infant who has difficulty regulating his/her states of arousal requires support for state transitioning and participation in infant occupations. Infants transition between six states of arousal including deep sleep, light sleep, drowsy, quiet alert, active alert, and crying state (Brazelton, 1984). An infant who is able to smoothly transition and achieve and maintain a quiet alert state can effectively engage in infant occupations. An infant's ability to demonstrate behavioral signs of coping and stability effects occupational engagement. An infant in the NICU demonstrates three behavioral cues including signs of stability, signs of coping, and signs of stress. Signs of stability include smiling, awake and relaxed, hands to face, minimal motor activity, pink color, and good heart and respiratory rate. Signs of coping include looking away, shifting to lower state of arousal, grasping, leg bracing, sucking, and yawning. Signs of stress include avoiding social interaction, gaze aversion, irritability, limb stiffening, fingers/toe splay, arching, tongue thrusting, color changes, changes in heart rate, respiratory rate, and oxygen saturation, and hiccoughs. Medical procedures and routine nursing care such as surgeries, heel sticks, IV placement, eye examinations, taking measurements and temperature, taking blood

pressure, and diaper changes are alarming and stressful to an infant in the NICU. Lastly, the environment in which an infant engages in effects occupational performance. The physical environment (light and sound) of the NICU is a source of stress for the infant and caregivers. Under the Occupational Therapy Practice Framework, occupational therapy's role in the NICU is to support infant's engagement in meaningful occupations through intervention approaches that create or promote, maintain, modify, prevent, and establish (American Occupational Therapy Association, 2002). Occupational therapists use family-centered, individualized, and developmentally supportive care while considering the medical complexity of the infant, the infant's behavioral cues and states, and the NICU environment in order to develop treatment strategies to optimize infant's occupational performance and developmental outcomes (Hunter, 1996).

The synactive theory of infant development is a current model applicable to infants in the NICU. The synactive theory identifies a hierarchical model of five subsystems including autonomic/physiological, motor, state, attention/interactive, and self-regulatory subsystems (Als, 1982). The autonomic/physiological subsystem includes the regulation of heart rate, respiration, color changes, and bowel movement. The motor subsystem includes the ability to make postural adjustments and movements. The state subsystem includes the ability to make smooth transitions between different levels of consciousness. The attentional/interactive subsystem refers to the ability to come to an alert and attentive state to take in environmental input. Lastly, the self-regulatory subsystem refers to the ability to maintain a balance between all five subsystems through self-consoling behaviors. When the subsystems are functioning well, infants are able to self-regulate (i.e. stability of the subsystems) to allow for engagement in occupations.

Infants born prematurely or diagnosed with a critical illness require support for physiological, motoric, state, attentional/interactive, and regulatory subsystems in order to engage in daily occupations. Support of state transitioning, behavior, and the environment is required to assist with organization and regulation of subsystems and to support the infant's participation in occupations to allow for developmental progression. When an infant is focusing on the need to maintain physiological stability, it limits their ability to control other subsystems and ability to self-regulate for occupational engagement.

Based on theory and principles of the synactive theory, the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) was established to provide education and consultative support in NICU settings to allow for a nuerodevelopmentally supportive, individualized, and family centered framework (Als, 2008). The focus of NIDCAP is to provide individualized care and environmental changes to enhance infant's strengths and self-regulation abilities based on the infant's behavioral cues. Studies that have explored the effectiveness of NIDCAP have found that the use of NIDCAP improved lung function, improved feeding behavior and physical growth, reduced intraventricular hemorrhage, reduced length of hospitalization, and improved neurobehavioral and neurophysiological functioning (Als et al, 1994; Fleisher et al, 1995; Buehler, Als, Duffy, McAnulty, & Liederman, 1995; Westrup, Kleberg, von Eichwald, Stjernqvist, & Lagercrantz, 2000; Als et al, 2003; Als et al, 2004). Studies have also shown better mental and psychomotor developmental scores on the Bayley Scale of Infant Development at three, five, and nine months corrected age (Als et al, 1986; Parker, Zahr, Cole, & Bracht, 1992, Als et al, 1994; Als et al, 2004) and improved gross and fine motor modulation, attention, social interaction, communication, and cognitive planning (Als et

al, 1994) on the Kangaroo Box Paradigm Play Episode for children that received individualized developmental care using principles of the synactive theory.

Since the late 1970's and early 1980's, occupational therapists have established an identity within the NICU environment to address infant needs based on the fundamental principles of the profession, centered around occupation (Vergara, 2002). Advancements in medical care and technology have allowed an increasing number of infants to survive extreme prematurity and medically complex conditions (Vergara, 2002). Occupational therapists in the NICU must have a basic knowledge of occupational therapy, pediatric experience, and specialized knowledge and skills related to the complex needs of high-risk infants, their families, and the NICU environment (The Commission on Practice, 2006). Occupational therapy practice in the NICU is very specialized; therefore many therapists use different models of practice and occupational therapeutic interventions in the NICU. Vergara (2002) states, “In the past few years, we have made improvements toward conceptualizing neonatal occupational therapy practice; however, we have yet to reach consensus about some fundamental principles and concepts” (p. 8). Literature is needed to document best practice and treatment strategies for infants and their families that ultimately supports and guides occupational therapy practice in the NICU. Therefore, the purpose of the following case study is to characterize occupational therapy intervention strategies for an infant with a critical illness by focusing on the infant’s response and developmental outcomes as well as highlight the benefits of standard of care occupational therapy interventions throughout hospitalization.

Case History

S.B. was born at 38 weeks gestational age with a diagnosis of left sided Congenital Diaphragmatic Hernia (CDH) to a 27 year-old mother with limited prenatal care including

history of alcohol and cigarette use during pregnancy. Apgar scores were 8 at one minute and 8 at five minutes after birth. S.B. experienced respiratory failure and pulmonary hypertension after birth requiring transfer to Cincinnati Children's Hospital Medical Center's Regional Center for Newborn Intensive Care for medial treatment and surgical repair. Repair of CDH was done five days after birth and surgical closure of the fascia was completed one week after the initial surgery to repair the CDH.

CDH is a defect in the diaphragm during fetal development in which the abdominal organs push into chest cavity compressing the lungs resulting in respiratory failure. The cause of CDH is thought to be a failure of the diaphragm to develop at nine to ten weeks of gestation resulting in intestinal organs to herniate through the defect in the diaphragm. Infants with CDH experience respiratory failure due to pulmonary hypertension and pulmonary hypoplasia. Pulmonary hypertension is caused from restriction of blood flow through the lungs thought to be caused by defects in the lung. Pulmonary hypoplasia is related to the abdominal organs presence in the chest cavity which causes the lungs to be severely undersized. Most infants with CDH are placed on a mechanical ventilator while more severe infants with CDH are placed on a heart/lung bypass machine. Once the infant is stable, surgery is required to place the abdominal organs into the proper position and repair the opening in the diaphragm. The incidence of CDH is estimated at approximately one in 2,500 to 5,000 live births with mortality approaching 75% including cases that never reach the treatment stage (Fetal Care Center of Cincinnati, 2005).

Infants diagnosed with CDH can experience a lengthy hospitalization with one study reporting the length of hospitalization averaging 74 days (Downard et al, 2003). Prolonged immobility, sedation, feeding intolerance, and often ventilator dependence are results of the medical complexity of CDH that impacts the length of hospitalization. Immobility, sedation, and

ventilator dependence can cause changes in soft tissue mobility, muscle tone, and positional and cervical preferences. Sweeney and Gutierrez (2002) state, “infants with medical fragility who remain in restrictive body positions experience prolonged joint compression with minimal refinement of mechanoreceptor action, predisposing them to skeletal deformation, muscle shortening and restricted joint mobility” (p. 60). Decreased acceptance of non nutritive and nutritive oral stimulation can result from peri and intra oral hypersensitivity due to long term ventilation, gastrointestinal intolerance, gastroesphageal reflux, and/or poor endurance. As a result, these infant can experience delayed oral intake requiring nasogastric tube placement and sometimes gastrostomy and nissen placement. The medical complexity of an infant with CDH and the consequences of lengthy hospitalization can result in limited occupational engagement. The balance between all five subsystems (autonomic/physiological, motor, state, attention/interactive, and self-regulatory subsystems) poses a challenge to a medically complex infant with CDH.

Infants with CDH have ongoing medical and neurodevleopmental concerns with 87% morbidity at hospital discharge, 61% at age one and 67% at age three (Friedman et al, 2008). These medical and neurodevleopmental problems with percentages at one and three years of age respectively include pulmonary (33.9, 36.7), cardiac (17.7, 10), gastrointestinal (50, 46.7), hypotonia (52.5, 86.2), hypertonia (9.8, 3.5), reduced strength (11.3, 3.3), motor asymmetry (30.7, 20), language problems (17.7, 60), sensory/hearing problems (0, 10), and social/behavioral problems (8.1, 10) (Friedman et al, 2008). Other research has identified neurological, nutritional, and respiratory long term outcomes of infants with CDH that includes developmental delay, cerebral palsy, growth retardation, gastroesophageal reflux, requiring

nutritional support, chronic lung disease and requiring oxygen at 2 years of age (Jaillard et al, 2003).

Occupational Therapy Evaluation

Orders for occupational therapy services to evaluate and treat S.B. were received, contact with nursing was initiated, and a chart review was completed. A standard evaluation form generated by the Cincinnati Children's Hospital Medical Center's Occupational and Physical Therapy Department was completed during a routine nursing assessment. Organizational skills including state transitioning, state behaviors, self-regulatory behaviors, and stress cues, muscle tone, soft tissue integrity, movement, and response to sensory stimulus were evaluated with results indicating S.B. is at risk for developmental delays due to complications that result from CDH and predicted prolonged hospitalization. The results of S.B.'s organizational skills, muscle tone, soft tissue integrity, movement, and response to sensory stimulus are recorded below.

Organizational Skills (state transitioning, behaviors, and stress cues)

Throughout the evaluation, S.B. remained in a light sleep state secondary to sedation to support his medical fragility. The only active movements observed were in response to care during the nursing assessment. S.B. displayed some behaviors of self-regulation. These behaviors included bringing hands to his face and pulling his extremities into flexion during stressful events for an attempt to calm himself. S.B. was unable to consistently self-regulate relying on support to calm himself. S.B. expressed multiple signs of stress including decreases in oxygen saturation, color changes, and limb stiffening during nursing care. His nurse provided breaks in care and the occupational therapy provided calm static touch to promote positive sensory input during nursing care to support S.B.'s state and behavior. In assessing S.B.'s organization skills, S.B. demonstrated signs of stress with inconsistent self-calming strategies

relying on support. Throughout the evaluation, S.B. positively responded to support through static touch as demonstrated by signs of coping and stability.

Muscle Tone, Soft Tissue Integrity, and Movement

Edema was present throughout S.B.'s anterior and posterior thoracic wall with soft tissue tightness palpable in his upper extremities and bilateral hip flexors. After S.B.'s head was passively rotated, he actively rotated his head back to midline as a result of possible discomfort or pain with cervical rotation. At rest while in supine, S.B.'s upper extremities were flexed, lower extremities were flexed and externally rotated, and his trunk was rotated with curvature of the spine to the right. In sidelying, he demonstrated upper extremity flexion, lower extremity external rotation, anterior pelvic tilt, and right trunk rotation. His spontaneous active movements were minimal and in response to care. His movements were of poor quality and guarded in response to pain during nursing care. S.B. demonstrated abrupt movements with an attempt to brace himself during care experiences. The identification of soft tissue tightness and edema put S.B. at risk for further tightness and limitations in active and passive movement. It was identified that S.B. is also at risk for cervical and positional preferences, plagiocephaly, and torticollis due to immobility, sedation, ventilator dependence, improper positioning, and complications of his body's physical and structural changes.

Response to Sensory Stimulus

At the time of evaluation, S.B. was unresponsive to visual, auditory, or tactile sensory stimuli as a result of sedation. S.B. did demonstrate signs of stress with vestibular input including decreased oxygen saturation and limb stiffening with handling, subtle movements, and position changes. The negative response to vestibular input including autonomic/physiological instability during the acute stage put S.B. at risk for continued difficulty tolerating movement and vestibular input.

Occupational Therapy Goals

Based on S.B.'s evaluation, five long term and ten short term goals to be reached by discharge were identified. One long term and three short term goals were identified for S.B.'s caregivers including parents and nurses to be reached by discharge. The short and long term goals set for S.B. and his caregivers have a significant impact on his future developmental milestones and preparation of skills for engagement in age related play occupations.

S.B.'s Goals

Long Term Goal-Demonstrate increased endurance

Short Term Goal-Keep vital signs stable for age with handling and active movement

Short Term Goal-Adjust to postural changes without respiratory compromise

Long Term Goal-Demonstrate smooth state transitions

Short Term Goal-Demonstrate ability to achieve calm alert state

Long Term Goal-Demonstrate age appropriate soft tissue mobility

Short Term Goal-Display age appropriate passive mobility of extremities

Short Term Goal-Display age appropriate passive trunk mobility

Long Term Goal-Demonstrate increased active movements

Short Term Goal-Demonstrate cervical rotation to the right and left

Long Term Goal-Demonstrate safe acceptance of nutrition consistently

Short Term Goal-Show interest in pre-feeding skills (oral stim and NNS on pacifier)

Short Term Goal-Show interest/feeding readiness cues prior to feeding

Short Term Goal-Coordinate suck, swallow breathe pattern independently

Short Term Goal-Have proper endurance with taking 20% needed nutrition volume

Caregivers Goals

Long Term Goal-Verbalization and demonstration of understanding of all caregiving

Short Term Goal-Verbalization and demonstration of calming strategies

Short Term Goal-Verbalization and demonstration of safe handling and positioning

Short Term Goal-Verbalization and demonstration of safe bottle feeding

Treatment Interventions

The primary occupational forms used during interventions included a radiant warmer bed and crib with mattress in a large room with 5-6 other crib spaces and medical equipment including a PICC line, A-Line, ventilator, oxygen through a nasal cannula, nasogastric tube, foley catheter, replogle tube, and monitors for temperature, heart rate, respiratory rate, and oxygen. Other occupational forms included standard hospital baby blankets, z-flo positioning devices, rocking chair, pacifier, milk, and bottle with an amber nipple. As medical status improved, the use of some medical equipment was decreased.

Occupational therapy intervention included providing static touch to promote positive sensory input during nursing assessments, calming techniques (static touch, containment, proprioceptive input, facilitating hands to face), soft tissue mobility, promoting a flexed position, therapeutic handling to promote optimal positioning and maximize respirations, positioning through variety of developmental positions, environmental changes, and caregiver education during the acute stage of hospitalization. During the subacute and transition to home stages, occupational therapy intervention included static touch, calming techniques (static touch, containment, proprioceptive input, facilitating hands to face), state transitioning, vestibular input and movement through various positions, therapeutic handling to promote optimal positioning and maximize respirations, positioning, environmental changes, caregiver education, therapeutic massage, soft tissue mobility through extremities, scapular, trunk, and pelvic regions, passive

range of motion, promoting controlled active movements of extremities, encouraging active cervical rotation, social interactions, peri-oral stimulation, non nutritive stimulation, and nutritive stimulation.

Research supporting NICU interventions throughout the stages of hospitalization with critically ill infants is limited. The therapeutic intervention of providing static touch with infants in the NICU is supported and widely used in NICU settings. A pilot study conducted to evaluate the effects of gentle human touch suggested that gentle human touch has no adverse effects on oxygen saturation or heart levels of preterm infants and that gentle human touch decreases levels of active sleep, motor activity and behavioral distress (Harrison, Olivet, Cunningham, Bodin, & Hicks, 1996). The effects of touch and promoting a flexed tucked position during routine nursing care of premature infants was researched with a finding that the intervention may reduce the infant's stress level which assists in maintaining stability in autonomoic, motor, and state systems (Hill, Engle, Jorgensen, Kralik, & Whitman, 2005). Another therapeutic intervention that has been supported in occupational therapy literature is the benefits of positioning with infants in the NICU. The primary goals of alternating positions (supine, prone, and sidelying) of infants in the NICU are to support posture and movement, optimize skeletal developmental and biomechanical alignment, provide controlled exposure to propricoeptive, tactile, and visual stimuli, and promote a calm regulated behavioral state (Sweeney and Gutierrez, 2002).

Therapeutic occupational interventions focused on five main areas including the ability to achieve a calm alert state, ability to tolerate vestibular input through handling, subtle movements, and position changes as demonstrated by signs of coping and stability, ability to maintain and improve soft tissue mobility as a result of immobility, ability to maintain and improve cervical rotation, and oral stimulation and feeding. Occupational therapy interventions changed daily as a

result of S.B.'s medical status and developmental needs. Occupational therapy interventions were provided four times a week for an average of 45 minutes to an hour a day by an occupational therapy student with supervision by an occupational therapist.

During the acute stage of hospitalization, S.B. had difficulty with tolerating general nursing care and state transitioning requiring support through static touch to calm and maintain stable vital signs. During many treatment sessions, S.B. demonstrated a decrease in oxygen saturation and inability to calm himself in response to nursing care. He required support through breaks in care and static touch to recover. Providing static touch before, during, and after nursing care assisted in promoting positive sensory input during painful, stressful, and uncomfortable care (medical and routine) experiences. Difficulty with state transitioning requiring calming through touch and handling, facilitating hands to face, promoting flexed positioning, promoting boundaries with positioning devices, decreasing environmental stimuli, containment, and proprioceptive input was provided during care experiences and at rest to promote self regulation. He continued to require support with state transitioning throughout the majority of his hospitalization. He was eventually able to maintain a quiet alert state for short periods in which he would quickly transition to a crying state. During the quiet alert states he was accepting of sensory input including visual and auditory stimuli to allow for social interactions. Calming before, during, and after care and assisting with state transitioning became the first area of focus for occupational therapeutic intervention with continued focus throughout hospitalization to allow for engagement in occupations. Tolerating general care and the ability to independently transition among sleep and wake states impacts S.B.'s ability to engage in his expected occupations of feeding, exploratory play, and social interactions.

A second area of focus for therapeutic intervention was on S.B.'s tolerance to vestibular input through handling, subtle movements, and position changes. During the acute stage, S.B. was routinely positioned in supine, sidelying, and semi sidelying positions with positioning devices with slow transitions and containment to promote tolerance. S.B.'s ventilation period lasted for 16 days. S.B. was transitioned out of bed with no tolerance to vestibular input after the acute stage. S.B. demonstrated signs of stress including an increased heart rate and respiratory rate when transitioned out of bed with an inability to cope. After S.B. began tolerating transitions out of bed, he had difficulty tolerating position changes while up in the therapist's arms (cradled, sidelying, supported upright, prone against therapists chest). S.B. eventually began favoring sidelying position on the therapists lap while swaddled due to improved physiological stability. Therapeutic interventions focused on slow transitioning in and out of bed and various position changes while up in the therapist's arms with containment and proprioceptive input with vestibular input. S.B.'s ability to tolerate various positions promotes engagement in infant occupations and caregiver occupations of feeding, nurturing, and holding. The ability to tolerate vestibular input also encourages future gross motor development including rolling and sitting upright.

A third area of focus of occupational therapy intervention was on S.B.'s ability to maintain and improve soft tissue mobility and asymmetrical posture and movement patterns from prolonged immobility, sedation, presence of edema, and structural changes in anatomy and physiology during the acute, subacute and transition to home stages. During the acute stage, S.B. presented with soft tissue tightness with shoulder elevation, elbow flexion, hip flexion and external rotation. During the subacute and transition to home stages, continued soft tissue tightness and the onset of asymmetrical postures were observed. S.B.'s left lower extremity was

fully extended and adducted while the right foot was comfortably flexed and externally rotated and resting on his left ankle. This asymmetrical posture at rest caused a pressure spot on his left ankle due to the resting of his right lower extremity on his left lower extremity. S.B. did demonstrate full passive range of motion throughout his extremities. Therapeutic intervention focused on positioning, the use of positioning devices, and soft tissue mobility to address the tightness and asymmetrical movement patterns in his extremities, scapular, trunk, and pelvic regions. Neurodevelopmental techniques and a variety of developmental positions with positioning devices encouraged the relaxation of soft tissue and promoted normal postures and movement patterns. Positioning devices promoted improved neurodevelopment and musculoskeletal alignment. Soft tissue mobility, with principles of myofascial release, promoted a gentle stretch through the extremities, scapular, trunk, and pelvic regions with an increased blood flow and heat to the tight areas. Limited mobility and asymmetrical movement patterns and postures impacts S.B.'s future motor development. Soft tissue tightness and asymmetrical posture and movement patterns through S.B.'s extremities can impact quality of movements, hand to mouth movements for self calming and midline play, shoulder stability for play and future developmental skills of creeping, crawling, and walking. Physical therapy was referred to assist with addressing the significant impact that his limitations and asymmetrical movement patterns and postures have on his future development.

A fourth area of focus for occupational therapeutic intervention was on S.B.'s ability to maintain and improve cervical rotation. During the acute stage, S.B. demonstrated minimal tolerance to cervical rotation as demonstrated by a resistance to mobility through the cervical region and active rotation to midline when passively rotated to the left. Once S.B. was transitioned out of bed for treatment sessions, a right cervical preference was notably observed.

Prolonged immobility including sedation and ventilator dependence, edema, improper positioning, and pain/discomfort associated with physical/structural changes have impacted his cervical rotation preference. Therapeutic interventions focused on passive cervical rotation due to restricted range of motion, encouraging active cervical rotation through tactile input and triggering the rooting reflex, soft tissue mobility through the cervical region, and positioning. S.B.'s position was changed every four hours with each nursing assessment and included supine and prone with left and right cervical rotation and left and right sidelying. Positioning during the acute stage consisted of routine positioning with positioning devices in supine, sidelying, and semi sidelying with cervical rotation to the left, right, and midline. Positioning during the subacute and transition to home stages consisted of positioning with positioning devices in supine and prone with left cervical rotation and left sidelying encouraged left cervical rotation and the elongation of the right sternocleidomastoid muscle. S.B.'s cervical rotation preference put S.B. at risk for positional plagiocephaly and torticollis. Limited cervical mobility can affect S.B.'s ability to develop midline orientation for midline play, scan his visual field, visually track moving objects, and respond to auditory stimuli during infant play.

The last area of focus for occupational therapeutic intervention was on S.B.'s tolerance to oral stimulation and acceptance of nutrition. Therapeutic interventions focused on peri and intra oral stimulation, non nutritive simulation with a pacifier, providing tastes, and providing bottle feeds with safe acceptance. Peri and intra oral stimulation with pacifier and gloved finger were provided to promote positive input in and around the mouth during the acute stages. After S.B. tolerated peri and intra oral stimulation, S.B. began initiating sucks on his pacifier with a strong suck and long sucking bursts. S.B. transitioned to tastes of milk dripped onto his pacifier as he was sucking with limited acceptance initially with progress after third attempt. When

transitioned to non nutritive suck and dripped tastes on an amber nipple of a bottle, S.B. wasn't accepting and unable to initiate a suck due to hypersensitivity to the change in nipple as demonstrated by arching, grimacing, and transition to lower state of arousal. S.B. eventually transitioned to an amber nipple and quickly accepted tastes and volumes of milk through a bottle while coordinating sucking, swallowing, and breathing. The slow progression of oral stimulation promoted desensitization techniques to allow for safe acceptance of bottle feeds. Speech therapy was referred to assist with addressing the evaluation of feeding and swallowing and provide interventions to enhance prelanguage development and feeding. Speech therapy and occupational therapy worked collaboratively to support S.B.'s pre feeding and feeding skills while also providing education to his caregivers. The progression to successful and safe acceptance of bottle feeding occurred with engagement in pre feeding interventions, therapeutic support of speech and occupational therapy, education of caregivers, and opportunities to practice feeding.

Meanings and Purposes of Therapeutic Interventions

Occupational therapeutic interventions provided during S.B.'s hospitalization were meaningful and purposeful to S.B. and his family. Therapeutic interventions that focused on the slow progression of movement and vestibular input, ability to maintain quiet alert state, and oral hypersensitivity allowed S.B. and his parents to engage in parent and infant interactions. When S.B. was unable to tolerate position changes and maintain a quiet alert state, S.B.'s parents were educated on how to provide calm static touch. Providing positive sensory input provided caregiver opportunities to assist with calming and transitions between sleep and wake states. The transition to tolerating position changes and movement allowed S.B.'s parents to engage in typical parental occupations of holding and nurturing their son. Interventions that focused on

S.B.'s oral hypersensitivity allowed S.B. the nutrients to grow and his parents the opportunity to engage in the occupation of feeding their son. All interventions provided had an impact on S.B.'s engagement in infant and age related play occupations and success with developmental milestones.

Outcomes of Interventions

S.B. was discharged 32 days after date of birth. At the time of discharge, S.B. demonstrated engagement in all of his expected occupations including feeding, socially interacting, exploratory play (visual, auditory, oral, tactile, proprioceptive, and vestibular), and procuring (care soliciting). S.B. occasionally demonstrated difficulty tolerating vestibular input and required occasional support to calm and transition between sleep and wake states. S.B. demonstrated minimal soft tissue tightness and active cervical rotation to the left and right. Before discharge, S.B. was displaying readiness cues for feeding and safely accepting all of his bottle feedings. S.B.'s caregivers demonstrated the ability to calm, position, and safely feed S.B. by discharge. Early interventions that focused on calming strategies, positioning, mobility, and oral stimulation promoted S.B.'s development and engagement in occupation.

S.B. was referred to the high risk follow up clinic at Cincinnati Children's Hospital Medical Center and early intervention for continued therapy. At a two week high risk follow up clinic appointment, S.B. demonstrated a symmetrical posture and typical movement patterns with active cervical rotation. After discussion with S.B.'s parents, S.B. continues to display readiness cues for feeding but only accepts two ounces of milk every 1 1/2 – 2 hours. It was determined that S.B. demonstrates gastroesphageal reflux as a complication associated with CDH and could be affecting his limited acceptance of nutrition at each feeding. S.B. will continue to be

monitored through the high risk follow up clinic and early intervention for continued development.

Conclusion

There were many benefits to the occupational therapeutic interventions provided throughout S.B.'s hospitalization with successful and safe engagement in all expected occupations. The control and stability of physiological/autonomic, motoric, states of arousal, and attentional/interactional subsystems promoted self regulation and engagement in occupations. The interventions provided throughout hospitalization supported the five subsystems including state transitions (sleep and wake states) and behaviors (stability, coping, and stress) as well as greatly impacting S.B.'s development and preparation for age related play occupations. The identification of cervical and positional preferences, soft tissue tightness, and asymmetrical posture and movement patterns and the implementation of occupational therapy intervention encouraged a decreased risk for future motor developmental delays. The early identification of oral hypersensitivity during the acute stage encouraged interventions to promote positive oral stimulation with a slow progression throughout hospitalization to allow for oral intake at discharge. S.B. experienced a positive outcome from the implementation of occupational therapeutic interventions throughout the stages of his hospitalization. Continued follow up after discharge is important to address his medical needs and development to promote engagement in infant and play occupations. Direct and consultative occupational therapy services provided during the acute and subacute stages of hospitalization are crucial to the development of critically ill infants and are essential for occupational engagement. The effects of prolonged immobility, sedation, feeding intolerance, and ventilator dependence need to be addressed during the acute stages and monitored throughout hospitalization. The interventions

provided throughout hospitalization of a critically ill infant provide therapists with a protocol to guide interventions during the acute and critical phases of hospitalization as well as the subacute and transition to home stages. Further research is needed to determine the effectiveness of each intervention throughout each stage of hospitalization including the acute stage to guide occupational therapy intervention for critically ill and premature infants in the NICU and to promote optimal developmental outcomes.

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Downard, C., Jaksic, T., Garza, J., Dzakovic, A, Nemes, L., & Jennings, R. (2003). Analysis of an improved survival rate for congenital diaphragmatic hernia. *Journal of Pediatric Surgery, 38,* 729-732.

Fetal Care Center of Cincinnati. (2005). Congenital Diaphragmatic Hernia/CDH. Retrieved April 1, 2008 from http://www.fetalcarecenter.org/fetal-surgery/cdh/default.htm.

Fleisher, B., VandenBerg, K., Constantinou, J., Heller, C., Benitz, W., Johnson, A., et al. (1995). Individualized developmental care for very-low-birth-weight premature infants. *Clinical Pediatrics, 34,* 523-529.

Friedman, S., Chen, C., Chapman, J., Jeruss, S., Terrin, N., Tighiouart, H. (2008). Neurodevelopmental outcomes of congenital diaphragmatic hernia survivors followed in a multidisciplinary clinic at ages 1 and 3. *Journal of Pediatric Surgery, 43*, 1035-1043.

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Appendix A

Annotated Bibliography

Als, H. (1986). A synactive model of neonatal behavioral organization: Framework for the assessment of neurobehavioral development in the premature infant and for support of infants and parents in the neonatal intensive care environment. *Physical and Occupational Therapy in Pediatrics, 6*, 3-53.

This article provides a description of the synactive model of neonatal behavioral organization including the assessment of the premature infant. This framework supports infants and parents in the NICU and was the primary framework used during for my case study report. This article provides level five evidence in which reports expert opinion.

Als, H. (1982). Toward a synactive theory of development: Promise for the assessment and support of infant individuality. *Infant Mental Health Journal, 3*, 29-243.

Abstract: A theoretical model to understand and assess the individual infant is presented. Its focus is on the dynamic, continuous interplay of various subsystems within the organism: the autonomic system, the motor system, the state organizational system, the attentional-interactive system, and the self-regulatory system. The organism forges ahead negotiating emerging developmental agenda while simultaneously seeking to attain a new level of modulated, functional competence. Developmentally salient aspects of the environment are actively sought as fuel in this process. This synactive model of development promises to be helpful in identifying specific ingredients of the early developmental process and in structuring specific supports for preventive and ameliorative work when difficulties in differentiation and regulation are identified. An assessment procedure to systematically identify difficult areas of modulation integration is briefly described and examples of environmental structuring are given.

This article originally highlights the synactive theory which is the primary theory used during my case study report. This article provides level five evidence in which reports expert opinion.

Als, H. (2008). *Newborn Individualized Developmental Care Assessment Program (NIDCAP): An education and training program for health care professionals*. Boston, MA: NIDCAP Federation International.

NIDCAP provides education and consultative support in NICU settings to allow for a nuerodevelopmentally supportive, individualized, and family centered framework. This program is based on theory and principles of the synactive theory.

Als, H., Duffy, F., McAnulty, G., Rivkin, M., Vajapeyam, S., Mulkern R., et al. (2004). Early experience alters brain function and structure. *Pediatrics, 113*, 846-857.

Abstract: *Objective.* To investigate the effects of early experience on brain function and structure. *Methods.* A randomized clinical trial tested the neurodevelopmental effectiveness of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). Thirty preterm infants, 28 to 33 weeks' gestational age (GA) at birth and free of known developmental risk factors, participated in the trial. NIDCAP was initiated within 72 hours of intensive care unit admission and continued to the age of 2 weeks, corrected for prematurity. Control (14) and experimental (16) infants were assessed at 2 weeks' and 9 months' corrected age on health status, growth, and neurobehavior, and at 2 weeks' corrected age additionally on electroencephalogram spectral coherence, magnetic resonance diffusion tensor imaging, and measurements of transverse relaxation time. *Results.* The groups were medically and demographically comparable before as well as after the treatment. However, the experimental group showed significantly better neurobehavioral functioning, increased coherence between frontal and a broad spectrum of mainly occipital brain regions, and higher relative anisotropy in left internal capsule, with a trend for right internal capsule and frontal white matter. Transverse relaxation time showed no difference. Behavioral function was improved also at 9 months' corrected age. The relationship among the 3 neurodevelopmental domains was significant. The results indicated consistently better function and more mature fiber structure for experimental infants compared with their controls. *Conclusions.* This is the first in vivo evidence of enhanced brain function and structure due to the NIDCAP. The study demonstrates that quality of experience before term may influence brain development significantly

This randomized controlled trial study investigated the effectiveness of NIDCAP. Five other randomized controlled trial studies have supported this study and reported effective use of NIDCAP theories with infants in the NICU. As a randomized controlled trial study, this study provides level one evidence in which the results can be considered credible and generalizable.

Als, H., & Gilkerson, L. (1997). The role of relationship-based developmentally supportive newborn intensive care in strengthening outcome of preterm infants. Seminars in *Perinatology, 21*, 178-189.

Abstract: This article details the conceptual framework, clinical application, and efficacy of a relationship-based developmentally supportive approach to newborn intensive care referred to as NIDCAP (Newborn Individualized Developmental Care and Assessment Program). Outcomes of the approach are reported in regard to infant health and development, reduction of hospital costs, and family adaptation. The approach is guided by a neurodevelopmental framework for understanding preterm infants and depends on the capacities of professionals to collaborate with one another and with families in support of the infants' medical, developmental, and emotional well-being. The primary vehicle for clinical implementation is detailed behavioral observation with subsequent recommendations for individualized caregiving based on the infant's current functioning and apparent developmental goals. A series of essential components of developmentally oriented caregiving are described, including strategies for coordinated discharge planning, and linkage to community services. The voices of individual clinicians highlight the process of change from protocol-based to relationship-based care.

This article provides a description of NIDCAP with principles of synactive model of neonatal behavioral organization and infant development. This framework supports infants and

parents in the NICU and was the primary framework used during for my case study report. This article provides level five evidence in which reports expert opinion.

Als, H., Gilkerson, L., Duffy, F., McAnulty, G., Buehler, D., Vandenberg, K., et al. (2003). A three-center, randomized, controlled trial of individualized developmental care for very low birth weight preterm infants: Medical, neurodevelopmental, parenting, and caregiving effects. *Journal of developmental and behavioral pediatrics : JDBP*, *24*, 399-408.

Abstract: Medical, neurodevelopmental, and parenting effects of individualized developmental care were investigated in a three-center, randomized, controlled trial. A total of 92 preterm infants, weighing less than 1250 g and aged less than 28 weeks, participated. Outcome measures included medical, neurodevelopmental and family function. Quality of care was also assessed. Multivariate analysis of variance investigated group, site, and interaction effects; correlation analysis identified individual variable contributions to significant effects. The results consistently favored the experimental groups. The following contributed to the group effects: shorter duration of parenteral feeding, transition to full oral feeding, intensive care, and hospitalization; lower incidence of necrotizing enterocolitis; reduced discharge ages and hospital charges; improved weight, length, and head circumferences; enhanced autonomic, motor, state, attention, and self-regulatory functioning; reduced need for facilitation; and lowered family stress and enhanced appreciation of the infant. Quality of care was measurably improved. Very low birth weight infants and their parents, across diverse settings, may benefit from individualized developmental care.

This randomized controlled trial study investigated the effectiveness of NIDCAP. Five other randomized controlled trial studies have supported this study and reported effective use of NIDCAP theories with infants in the NICU. As a randomized controlled trial study, this study provides level one evidence in which the results can be considered credible and generalizable.

Als, H., Lawhon, G., Brown, E., Gibes, R., Duffy, F., McAnulty, G., et al. (1986). Individualized behavioral and environmental care for the very low birth weight preterm infant at high risk for bronchopulmonary dysplasia: Neonatal intensive care unit and developmental outcome. *Pediatrics*, *78*, 1123-1132.

Abstract: We hypothesize that the respiratory and functional states of the very low birth weight infant with bronchopulmonary dysplasia can be improved in the neonatal intensive care unit by prevention of inappropriate sensory input. To test this hypothesis, we developed for preterm newborns a behavior observation method that catalogues specific reaction patterns according to putative stress and relaxation behaviors. We then collected behavioral information and heart rate, respiratory rate, and transcutaneous PO_2 readings before, during, and after routine care-giving interventions. Eight control and eight experimental infants were selected for study based on the following criteria: birth weight <1,250 g, gestational age <28 weeks, on the respirator >24 hours in first 48 hours of life at ≥0.6O FiO_2 for more than two hours during first 48 hours of life. Additionally, the two groups were comparable on other medical and demographic variables, including severity of respiratory status for the first ten days and incidence of

intraventricular hemorrhage, patent ductus arteriosus, and socioeconomic status. Systematic observations were conducted on days 10, 20, and 30 after birth and at 36 and 40 weeks postconception. For the intervention infants, our observations were discussed with the infants' primary nurses, and individualized modifications for each infant's care plan were implemented based on these observations. Experimental infants showed significantly briefer stays on the respirator ($P < .01$) and in increased FiO_2 ($P < .05$). Their feeding behavior was normalized significantly earlier ($P < .01$). Experimental infants also showed significantly better behavioral regulation scores at 1 month after their mothers' estimated dates of confinement (post-EDC), as measured with the Assessment of Preterm Infants' Behavior, significantly better Mental and Psychomotor Developmental Indices at 3, 6, and 9 months post-EDC, as measured with the Bayley Scales of Infant Development, and significantly better behavioral regulation scores at 9 months post-EDC, as measured in a videotaped play observation. Measurements of weight, height, and head circumference at 3, 6, and 9 months post-EDC showed no differences. All assessments were performed by one of two trained testers not familiar with the goals of the study or the group status of the infant. These results support the hypothesis that very low birth weight preterm babies profit significantly both medically and developmentally from individualized behavioral care in the neonatal intensive care unit.

This study investigates the long term effects of NIDCAP and theories of synactive theory. This article was cited to identify the positive outcomes of NIDCAP in a NICU setting and to support the use of the model with my case study. This provides level two evidence in which the two groups studied were controlled.

Als, H., Lawhon, G., Duffy, F., McAnulty, G., Gibes-Grossman, R., & Blickman, J. (1994). Individualized developmental care for the very low-birth-weight preterm infant. Medical and neurofunctional effects. *Journal of the American Medical Association, 272*, 853-858.

Abstract: OBJECTIVE: To investigate the effectiveness of individualized developmental care in reducing medical and neurodevelopmental sequelae for very low-birth-weight infants. DESIGN--Randomized controlled trial. SETTING--Newborn intensive care unit. PATIENTS--Thirty-eight singleton preterm infants, free of known congenital abnormalities, weighing less than 1250 g, born before 30 weeks' gestation, mechanically ventilated within 3 hours of delivery and for more than 24 hours in the first 48 hours, randomly assigned to a control or an experimental group. INTERVENTION--Caregiving by nurses specifically trained in individualized developmental care; observation and documentation of the infants' behavior within 12 hours of admission, and subsequently every 10th day; developmental care recommendations and ongoing clinical support for the nurses and parents based on regular observation of the infant by developmental specialists; and the availability of special caregiving accessories. MAIN OUTCOME MEASURES--Medical outcome, including average daily weight gain; number of days the infant required mechanical ventilation, oxygen, gavage tube feeding, and hospitalization; severity of retinopathy of prematurity, bronchopulmonary dysplasia, pneumothorax, and intraventricular hemorrhage; pediatric complications; age at discharge; and hospital charges. Neurodevelopmental outcome, including Assessment of Preterm Infants' Behavior scale and quantified electroencephalography (2 weeks after due date); and Bayley Scales of Infant Development and Kangaroo Box Paradigm (9 months after due date). RESULTS--The infants in the experimental group had a significantly shorter duration of

mechanical ventilation and supplemental oxygen support; earlier oral feeding; reduced incidence of intraventricular hemorrhage, pneumothorax, and severe bronchopulmonary dysplasia; improved daily weight gain; shorter hospital stays; younger ages at hospital discharge; and reduced hospital charges compared with the infants in the control group. At 2 weeks after their due dates, these infants also showed improved autonomic regulation, motor system functioning, self-regulatory abilities, and visual evoked potential measures; and at 9 months, they had improved Bayley Mental and Psychomotor Developmental Index scores, as well as Kangaroo Box Paradigm scores. CONCLUSION--Very low-birth-weight preterm infants may benefit from individualized developmental care in the neonatal intensive care unit in terms of medical and neurodevelopmental outcome.

This randomized controlled trial study investigated the effectiveness of NIDCAP. Five other randomized controlled trial studies have supported this study and reported effective use of NIDCAP theories with infants in the NICU. As a randomized controlled trial study, this study provides level one evidence in which the results can be considered credible and generalizable.

American Occupational Therapy Association. (2002). Occupational therapy practice framework: Domain and process. *American Journal of Occupational Therapy, 56,* 609–639.

Abstract: Occupational therapy is an evolving profession. Over the years, the study of human occupation and its components has enlightened the profession about the core concepts and constructs that guide occupational therapy practice. In addition, occupational therapy's role and contributions to society have continued to evolve. The Occupational Therapy Practice Framework: Domain and Process (also referred to in this document as the Framework) is the next evolution in a series of documents that have been developed over the past several decades to outline language and constructs that describe the profession's focus.

Anzalone, M. E. (1994). The Issue Is-Occupational therapy in neonatology: What is our ethical responsibility? *American Journal of Occupational Therapy, 48,* 563-566.

Abstract: There is a continuing debate in occupational therapy about specialization (Ahlschwede 1992; Gillette & Kiehofner, 1979). This special issue of the American Journal of Occupational Therapy on occupational therapy in the neonatal intensive care unit (NICU) provides an opportunity for another chapter in that debate. It is essential that the occupational therapist practicing in neonatology have specialized training. The knowledge, skills, and clinical reasoning required for safe, ethical, and effective occupational therapy practice in that setting demand a clinician with abilities far beyond that of the generalist. Although the neonatal occupational therapist has the same domains of concern as other occupational therapist (i.e., performance of developmentally appropriate roles or occupations and the performance components underlying function), the specialized knowledge required to provide skillful intervention in neonatology and competently address those domains of function is not to be found exclusively in the occupational therapy literature or in entry-level curricula. Occupational therapists do provide a unique perspective on the treatment of neonates and their families in the NICU. We look at the neonate in a holistic way, considering not only the underlying performance components, such as motor or sensory performance, but also how those components

are organized in relation to each other and into functional activities. We also consider how the family can assume a modified parental role within the NICU environment (American Occupational Therapy Association [AOTA] , 1993: Christiansen & Baum, 1991). The perspective of the occupational therapist is invaluable in the NICU, but only if it is provided by a knowledgeable therapist capable of understanding the unique needs of the infants, families, and environments found here.

This article identifies the role of occupational therapy to support occupations of infants and occupations of caregivers. Occupational therapists working in the NICU must have knowledge, skills, and clinical reasoning to provide effective and safe occupational therapy practice in the NICU.

Beachy, J.M. (2003). Premature infant massage in the NICU. *Neonatal Network, 22*(3), 39-45.

Abstract: Infant massage therapy is an inexpensive tool that should be utilized as part of the developmental care of the preterm infant. Nurses have been hesitant to begin massage therapy for fear of overstimulating the infant and because there has been insufficient research to prove its safety. Recent research, however, has shown that the significant benefits of infant massage therapy far outweigh the minimal risks. When infant massage therapy is properly applied to preterm infants, they respond with increased weight gains, improved developmental scores, and earlier discharge from the hospital. Parents of the preterm infant also benefit because infant massage enhances bonding with their child and increased confidence in their parenting skills. This article discusses the benefits and risk of massage for preterm infants and their families and explains how to implement massage therapy in the neonatal intensive care setting.

This article identifies the occupational therapy intervention of infant massage used in the NICU. The article identifies recent research and benefits of infant massage. This article provides level five evidence.

Becker, P., Grunwald, P., Moorman, J., & Stuhr, S. (1993). Effects of developmental care on behavioral organization in very-low-birth-weight infants. *Nursing Research*, *42*, 214-220.

Abstract: The purpose of this study was to determine whether modifying care to reduce stressors in the neonatal intensive care unit and support infant development affected physiological, motor, and behavioral state organization. Twenty-one infants weighing less than 1501 g were studied prior to a nursing staff-training program (control) and 24 infants were studied posttraining (study). Nurses were taught to lower environmental stress, reduce procedural stress, and facilitate motor and sleep-wake organization. Oxygen saturation, motor activity, posture, and sleep-wake states were measured biweekly during routine care. Study infants showed higher oxygen saturation levels, fewer disorganized and jerky movements, more flexor movements, more flexed posture, and more alert-wakefulness than controls. Results suggest that this approach to care may have potential to improve behavioral organization during the preterm period.

This article investigated the effectiveness of environmental changes to reduce stress, reducing procedural stress and facilitating motor and sleep wake organization. This article suggests that making changes to the environment, reducing procedural stress, and facilitating

motor and sleep wake oraganization does have potential to improve organization for infants in the NICU. Environmental changes, procedural stress and facilitating motor and sleep wake organization were addressed during the case study's hospitalization. This article provides level three evidence.

Blackburn, S., & Bakewell-Sachs, S. (2003). Understanding the behavior of term infants. *March of Dimes Perinatal Nursing Education*, 1-14.

This article reviews the six states of consciousness of a newborn. States consist of sleep and awake states. The sleep states include quiet and active sleep. The awake states include drowsy, quiet alert, active alert, and crying. This article identifies characteristics of each state and the benefits of state modulation. This article also contains factors that could influence an infant's state such as touch, visual factors, auditory factors, proprioceptive factors, environmental temperature, sucking, stressful events, internal physiologic needs, pathologic conditions, and drugs. Understanding the behavior of infants is critical to providing occupational therapy intervention with preterm and critically ill infants. This article provided important information to understand before providing any interventions at the start of the practicum. Observing and identifying behaviors became a focus at the start with continued focus to support behavior throughout the practicum.

Brandon, D., Ryan, D., & Barnes, A. (2007). Effect of environmental changes on noise in the NICU. *Neonatal Network, 26*, 213-218.

Abstract: To evaluate the effect of changes in the NICU environment on sound levels. DESIGN: A prospective quasi-experimental design evaluated sound levels in a 43-bed NICU. Decibel levels were monitored utilizing a data-logging dosimeter for 24 hours weekly over 12 months. Sound levels were also measured inside four different incubator models. SAMPLE: Forty-four 24-hour decibel recordings were obtained in one of eight randomly selected four-bed pods. In addition, a single 1-hour recording was obtained in four different models of vacant incubators. Main outcome variable:Ambient sound levels. RESULTS: Decibel levels were analyzed to identify changes in noise levels following alterations in the NICU environment. Installation of motion-sensing motorized paper towel holders significantly increased levels at beds closest to the towel dispensers, as did the trial of a new communication system. Decibel levels in four different incubators revealed varying noise levels. This study suggests that all environmental changes must be monitored to ensure that they reduce rather than increase noise levels.

This article investigated the effect of environmental stimuli in the NICU environment. The study suggests that auditory stimuli must be reduced to support the NICU environment. Environmental changes including reducing auditory stimuli were addressed throughout the case study's hospitalization. This article provides level three evidence.

Brazelton, T. (1984). Neonatal Behavioral Assessment Scale, Second Edition. *Clinics in developmental medicine: No. 88*. Philadelphia: Lippincott, Williams & Wilkins.

The Neonatal Behavioral Assessment Scale identifies the transition between six states of arousal including deep sleep, light sleep, drowsy, quiet alert, active alert, and crying state. An infant who has difficulty regulating his/her states of arousal requires support for state transitioning and participation in infant occupations. This article provided important information to understand before providing any interventions at the start of the practicum. Observing and identifying behaviors became a focus at the start with continued focus to support behavior throughout the practicum.

Buehler, D., Als, H., Duffy, F., McAnulty, G., & Liederman, J. (1995). Effectiveness of individualized developmental care for low-risk preterm infants: Behavioral and electrophysiological evidence. *Pediatrics, 96*, 923-932.

Abstract: *Objective*. We assessed the effectiveness of individualized developmental support in the special care nursery for low-risk preterm infants. *Setting*. A university-affiliated teaching hospital. *Participants*. Twelve healthy full-term infants, and 24 low-risk preterm infants randomly assigned to a control or an experimental group. *Design*. The preterm control group received standard care and the preterm experimental group received individualized developmental care at the same special care nursery. *Outcome Measures*. Medical, behavioral (Assessment of Preterm Infants' Behavior and Prechtl's Neurological Examination of the Full-Term Newborn Infant), and electrophysiologic outcome (using quantitative electroencephalography with topographic mapping) of all three groups was assessed 2 weeks after the expected due date. *Results*. No between-or among-group medical differences were seen for this low-risk, healthy sample. The preterm experimental group showed behavioral and electrophysiologic performances comparable to those of the full-term group, whereas the preterm control group performed significantly less well. Behavioral measures suggested significantly poorer attentional functioning for the preterm control group. Electrophysiologic results implicated the frontal lobe. *Conclusions*. Individualized developmental intervention supports neurobehavioral functioning as measured at 2 weeks post-term. It appears to prevent frontal lobe and attentional difficulties in the newborn period, the possible causes of behavioral and scholastic disabilities often seen in low-risk preterm infants at later ages.

This randomized controlled trial study investigated the effectiveness of NIDCAP. Five other randomized controlled trial studies have supported this study and reported effective use of NIDCAP theories with infants in the NICU. As a randomized controlled trial study, this study provides level one evidence in which the results can be considered credible and generalizable.

Caretto, V., Topolski, K., Linkous, C., Lowman, D., & Murphy, S. (2000). Current parent education on infant feeding in the neonatal intensive care Unit: The role of the occupational therapist. *American Journal of Occupational Therapy, 54*, 59-64.

Abstract: The purpose of this study was to describe current trends in parent education on infant feeding in the neonatal intensive care unit (NICU) and to clarify the role of the occupational therapist in educating parents. Questionnaires were mailed to 190 neonatologists across the United States who were asked to forward it to a NICU occupational therapist. The

questionnaire gathered descriptive information about the structure of parent education in the NICU, the role of the occupational therapist in providing parent education, and demographics about respondents and their NICU's. The response rate was 53% (n=100). All 100 hospitals responding provided parent education in some form, and most included a variety of topics and teaching methods. Occupational therapists were on the NICU team at 74 of the hospitals and were identified third most frequently as provider of parent education. The occupational therapists were most frequently identified as responsible for teaching about positioning, infant development, and infant states and cues and were highly involved in educating parents about feeding. Current parent education programs in NICUs are comprehensive in scope. Occupational therapists' role in educating parents about infant care and feeding consists of a focus on certain topics where occupational therapists have specialized skills and education. Occupational therapists are recognized by their NICU colleagues as providers of parent education, but this study suggests that the occupational therapists' role may not be clearly understood by other NICU professionals.

This article provided information on the importance of educating parents on infant feeding in the NICU and educating NICU professional on OT's role in the NICU. Education on the role of OT and feeding was provided to the nursing caregivers and parent during the case study's hospitalization. This article provides level five evidence.

Downard, C., Jaksic, T., Garza, J., Dzakovic, A, Nemes, L., & Jennings, R. (2003). Analysis of an improved survival rate for congenital diaphragmatic hernia. *Journal of Pediatric Surgery*, *38*, 729-732.

Abstract: Congenital diaphragmatic hernia(CDH) is a condition associated with significant mortality. This study examines the survival rate of neonates with CDH treated by a multidisciplinary team in a single pediatric hospital. Actual survival rate is compared with predicted outcome based on severity of illness.

This article identifies the survival rate of infants with CDH as well as the average hospital stay. This article was cited to support the fact that infants with CDH experience prolonged hospitalization with an unsure outcome. This article provides level four evidence in which involves analysis of outcomes.

Dudek-Shriber, L. (2004). Parent stress in the neonatal intensive care unit and the influence of parent and infant characteristics. *American Journal of Occupational Therapy*, *58*, 509-520.

Abstract: This study investigated the stress experienced by parents in the neonatal intensive care unit (NICU), the infant and parent characteristics that resulted in different stress responses, and the characteristics that were predictive of stress. The Parental Stress Scale: Neonatal Intensive Care Unit was used to measure the stress of 162 parents. A Parent/Infant Demographic sheet provided information for determining which characteristics resulted in different responses and which variables were stress predictors. The highest levels of stress experienced were in the relationship with baby–parental role area, and regarding how the baby looked and behaved. The infant characteristic of gestational age resulted in significantly different

scores concerning the baby's appearance and behavior. Consistent predictors of stress were length of stay, extreme prematurity, and a cardiovascular diagnosis. Identifying the stressors parents experience can assist NICU therapists in intervention planning. Family-centered care that addresses stressors concerning their roles and their understanding of their infant should be emphasized.

Fetal Care Center of Cincinnati. (2005). Congenital Diaphragmatic Hernia/CDH. Retrieved April 1, 2008 from http://www.fetalcarecenter.org/fetal-surgery/cdh/default.htm.

This website provides an overview of CDH including the definition, causes, incidence, diagnosis, management, fetal surgery and intervention. The mother of the case study was seen by the Fetal Care Center of Cincinnati with continued follow-up.

Fleisher, B., VandenBerg, K., Constantinou, J., Heller, C., Benitz, W., Johnson, A., et al. (1995). Individualized developmental care for very-low-birth-weight premature infants. *Clinical Pediatrics, 34,* 523-529.

Abstract: Forty very-low-birth-weight neonatal intensive care unit (NICU) infants with birth weights ≤1,250 g were randomly assigned to treatment or control groups. Behavior of the treatment infants was systematically evaluated, and individualized developmentally oriented care plans were implemented to enhance stability. Treatment babies required fewer days of intermittent mandatory ventilation and continuous positive airway pressure and achieved full enteral feedings sooner. Length of hospital stay and hospital charges were less for treatment than control infants. There were favorable effects on treatment infants' behavioral performance at 42 weeks' postconceptional age. These results support the hypothesis that behaviorally sensitive, developmentally oriented care improves medical and neurodevelopmental outcome in the NICU.

This randomized controlled trial study investigated the effectiveness of NIDCAP. Five other randomized controlled trial studies have supported this study and reported effective use of NIDCAP theories with infants in the NICU. As a randomized controlled trial study, this study provides level one evidence in which the results can be considered credible and generalizable.

Friedman, S., Chen, C., Chapman, J., Jeruss, S., Terrin, N., Tighiouart, H. (2008). Neurodevelopmental outcomes of congenital diaphragmatic hernia survivors followed in a multidisciplinary clinic at ages 1 and 3. *Journal of Pediatric Surgery, 43*, 1035-1043.

Abstract: Infants who survive congenital diaphragmatic hernia (CDH) repair may have ongoing medical and neurodevelopmental morbidity after hospital discharge. We evaluated the relationship between medical and neurodevelopmental outcomes of CDH survivors seen in a multidisciplinary clinic at ages 1 and/or 3. From January 1997 to December 2004, 69 (61%) of 112 CDH survivors were followed in our CDH clinic at ages 1 and/or 3. Medical issues (cardiac, pulmonary, gastrointestinal) were tabulated at hospital discharge and at follow-up. Neurodevelopmental data were obtained from clinic assessments by a neurodevelopmental pediatrician. Descriptive results were summarized for each cohort. Multivariate analyses were

performed to identify predictors of motor problems at age 1. Of the 69 study participants, 64% were male, 75% had left-sided CDH, 17% had cardiac anomalies, and 25% had other congenital malformations. Nearly all required ventilator management (99%) with a median ventilator time of 14 days (range, 1-54 days); 30% required extracorporeal membrane oxygenation. While 87% of patients had medical issues at hospital discharge, 61% and 67% had medical issues at ages 1 and 3, respectively. Pulmonary problems were noted in 34% and 33% of the ages 1 and 3 cohorts, respectively. Motor and language problems were detected in 60% and 18% of the age 1 cohort and 73% and 60% of the age 3 cohort, respectively. Multivariate analysis found ventilator time as the only independent predictor of motor problems at age 1 (odds ratio, 1.12 per day; 95% confidence interval, 1.05-1.20; $P < .01$). Young CDH survivors continue to have ongoing medical problems and a high incidence of motor and language problems. Duration of neonatal ventilatory support was a significant predictor of motor problems at age 1. Prospective studies are needed to confirm these findings.

This article identifies the medical and neurodevelopmetnal outcomes of CDH survivors at 1 and 3 years of age. To assist in occupational therapy's role with infants with CDH, identifying long term developmental outcomes was very important. This article was cited in my case study article. This study provides level two evidence in which two groups are controlled.

Grenier, I., Rigsby, R., Vergara, E., & Lester, B. (2003). Comparison of motor self-regulatory and stress behaviors of preterm infants across body positions. *American Journal of Occupational Therapy, 57,* 289-297.

Abstract: Occupational therapists working with infants in neonatal intensive care units (NICUs) make positioning recommendations to optimize self-regulation, with little published data supporting this practice. In this retrospective descriptive study, 15 hospitalized preterm infants (Mgestational age = 32 weeks) were videotaped during noncaregiving periods in order to record the frequency of specific behaviors in relation to six infant positions (prone nested, prone un-nested, side-lying nested, side-lying un-nested, supine nested, and supine un-nested). Behaviors coded were those that suggest infant stress or motor efforts at self-regulation, as defined for the original study. Mixed effects regressions and post-hoc Tukey Honestly Significant Difference tests were used to analyze the data, after the calculation of a ratio of the number of behaviors in each position. Higher ratio values reflect a greater occurrence of behaviors. The number of motor self-regulatory and stress behaviors were related to infant position, with the highest ratios of behaviors observed in side-lying un-nested and the lowest in prone nested. Behavior ratios did not differ between prone un-nested and prone nested, nor between supine un-nested and supine nested. More self-regulatory and stress behaviors were related to longer periods of fussing and crying. Longer periods of light sleep were related to fewer stress behaviors. Infants performed the fewest stress behaviors in prone nested, prone un-nested, or side-lying nested. These positions may benefit infants in the NICU by reducing the need for motor-based self-regulatory behaviors and potentially conserving energy for growth.

This article identified positions that benefit infants in the NICU by conserving energy and the need for motor based self regulatory behaviors. The positions that allowed longer periods of sleep and fewest stress behaviors included prone nested, prone un-nested and sidelying nested. These positions were implemented during the case study's hospitalization with focus on reducing stress behaviors.

Harrison, L., Olivet, L., Cunningham, K., Bodin, M., & Hicks, C. (1996). Effects of gentle human touch on preterm infants: Pilot study results. *Neonatal Network, 15*, 35-42.

Abstract: A pilot study was conducted to evaluate the effects of gentle human touch (GHT) provided for 15 minutes a day to preterm infants from day 7 to day 12 of life. The study suggested that GHT has no adverse effects on the oxygen saturation or heart rate levels of small preterm infants and that GHT has a soothing effect as evidenced by decreased levels of active sleep, motor activity, and behavioral distress. These results can provide NICU nurses with a basis for guiding parents in their early interactions with preterm infants in the NICU.

This pilot study evaluated the effects of gentle human touch on infants in the NICU with results indicating that gentle human touch has no adverse effects on oxygen saturation or heart rate levels but does have a positive effect of decreased levels of active sleep, motor activity and behavioral distress. This occupational therapy intervention was provided throughout the case study's hospitalization. Human touch was soothing for the case study and decreased behavioral distress, decreased motor activity, and promoted state transitioning. This article provides level two evidence.

Hill, S., Engle, S., Jorgensen, J., Kralik, A., & Whitman, J. (2005). Effects of facilitated tucking during routine care of infants born preterm. *Pediatric Physical Therapy, 17*, 158-163.

Abstract: The purpose of this study was to compare stress responses of infants born preterm during routine nursing assessments performed under two conditions. One condition incorporated a second caregiver supporting the infant in a facilitated tucked position, whereas the second condition did not. METHODS: A convenience sample of 12 infants born preterm, ages 25 to 34 weeks postconceptual age on the day of testing (mean = 30.9 weeks), were evaluated using the Premature Infant Pain Profile (PIPP), during the two caregiving conditions. For each trial, the infant received a PIPP score. The level of significance was set at $p = 0.05$. RESULTS: A significant difference ($p = 0.013$) existed between the two testing positions as measured by the PIPP. Nine of the 12 infants received a lower PIPP score with facilitated tucking during routine care assessments. CONCLUSIONS: By incorporating facilitated tucking during routine care events, the stress level of the infants born preterm may be reduced. When the infants' stress levels are reduced, they may be better able to maintain stability in their autonomic, motor, and state systems.

This article identifies the effects of promoting a flexed position and containing an infant during routine nursing care. This therapeutic intervention was provided for my case study report. This study provides level two evidence in which two groups are controlled.

Hunter, J. (1996). Clinical interpretation of "Education and training of occupational therapist for neonatal intensive care units". *American Journal of Occupational Therapy, 50*, 495-503.

The survey results described by Dewire, White, Kanny, and Glass (19%) should alarm and motivate occupational therapists concerned about quality, safety, and efficacy of

occupational therapy practice in the neonatal intensive care unit (NICU). Their study clearly illustrates that current practice in the NICU often does not reflect best practice, as suggested by the American Occupational Therapy Association (AOTA) NICU Task Force Position Paper, Knowledge and Skills for the Occupational Therapist in the Neonatal Intensive Care Unit (AOTA, 1993). Given such findings that nearly one-fifth (17%) of NICU therapists begin neonatal practice with no experience or training and the lack of consistent standards for neonatal training or practice, the need to pursue these issues should become a priority mandate for occupational therapists and the profession.

This article identifies occupational therapy's role in the NICU. This article was cited in my case study report. This article provides level five evidence in which reports expert opinion.

Jacobs, S., Sokol, J., & Ohlsson, A. (2002). The newborn individualized developmental care and assessment program is not supported by meta-analyses of the data. *Journal of Pediatrics, 140*, 699-706.

Abstract: Objectives: To systematically review the effectiveness of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) as compared with conventional care to improve long-term neurodevelopmental outcomes or short-term medical and neurodevelopmental outcomes in preterm and/or low birth weight infants. Study design: With the use of standard systematic review methodology, all randomized, controlled trials (RCTs) and prospective cohort studies evaluating in-hospital developmental care based on the framework of NIDCAP in preterm and/or low birth weight infants were identified. The quality of the RCTs was assessed. Meta-analyses were performed by using relative risk and risk difference for dichotomous data and weighted mean difference for continuous data with 95% confidence intervals.Results: Five RCTs (n = 136) and 3 phase-lag cohort studies (n = 185) met inclusion criteria. School-age neurodevelopmental outcomes after NIDCAP have not been reported. Meta-analyses of medical outcomes showed a statistically significant benefit of NIDCAP on requirement for supplemental oxygen. Neurodevelopmental outcome was improved at 9 or 12 months but not at 2 years. Conclusions: There is insufficient evidence to support the NIDCAP to improve medical and neurodevelopmental outcomes of preterm infants.

This article identifies that there is insufficient evidence to support NIDCAP's use in improving outcomes of preterm infants. The article did identify benefits of NIDCAP on requirement for supplemental oxygen and improved neurodevelopmental outcomes at 9 and 12 months. This article provides level two evidence.

Jaillard, S., Pierrat, V., Dubois, A., Truffert, P., Lequien, P., Wurtz, A. (2003). Outcome at 2 years of infant with congenital diaphragmatic hernia: A population-based study. *The Annals of Thoracic Surgery, 75,* 250-256.

Abstract: Management of neonates with congenital diaphragmatic hernia (CDH) has undergone many changes associated with increased survival of high-risk CDH. However, little is known about the long-term outcome of CDH infants. METHODS: Follow-up was performed in 85 newborn infants with CDH admitted in our neonatal intensive care unit between January 1991 and December 1998. Early (< 2 months) and late mortality (> or = 2 months), and respiratory,

nutritional, musculoskeletal, and neurosensory outcome at 2 years were recorded. RESULTS: Surgical repair was performed in 59 infants (69%) at a median postnatal age of 124 (range, 38 to 246) hours. Extracorporeal membrane oxygenation was used in 26 (30%) newborn infants. Survival at 2 years was 51 of 85 (60%) (early death, 28/85 [33%]; late death, 6/85 [7%]). Late deaths occurred because of persistent pulmonary hypertension or iatrogenic complications. Twelve of 51 (24%) newborn infants were oxygen dependant at the postnatal age of 28 days, and 1 of 51 (1.9%) was still oxygen dependant at 2 years. Growth failure was noted in 9 of 51 (18%), mainly related to severe gastroesophageal reflux and oral aversion. Scoliosis was diagnosed in 2 infants. Neurologic examination at 2 years was normal in 45 of 51 (88%). Cerebral palsy and developmental delay were observed in 2 and 4 infants, respectively. Four infants (8%) experienced associated problems. Respiratory, nutritional, and musculoskeletal morbidity was higher in infants treated by extracorporeal membrane oxygenation ($p < 0.05$). CONCLUSIONS: CDH infants are at risk for adverse nutritional and respiratory outcome. Despite severe respiratory failure at birth, prolonged oxygen therapy above 2 years of age is uncommon. Conversely, failure to thrive related at least in part to gastroesophageal reflux and oral dysfunction remains the major problem at 2 years of age. However, both nutritional and respiratory problems tend to improve with age.

This article identified the long term outcomes of CDH at 2 years of age. To assist in occupational therapy's role with infants with CDH, identifying long term developmental outcomes was very important. This article was cited in my case study article. This study provides level two evidence in which two groups are controlled.

Lawrence, J. (1993). The development of a tool to assess neonatal pain. *Neonatal Network, 12*, 59-66.

Abstract: The objectives of this study were to (1) develop a behavioral assessment tool for the measurement of *pain* in the preterm and full-term neonate; (2) establish the construct and concurrent validity, interrater reliability, and internal consistency of the tool; and (3) examine the relationship between the pain scores and infant characteristics. Thirty-eight infants contributed to the 90 procedures videotaped for the study. The Neonatal Infant Pain during, and after each intrusive procedure. The significant difference in NIPS scores over time indicates that the scale provides a measurement of intensity of infant responses to intrusive procedures. Concurrent validity was established by correlations, ranging from .53 to .84, between NIPS scores at each minute of observation and scores on the Visual Analogue Scale. Interrater reliability was high: Pearson correlations ranged from .92 to .97 across successive minutes of observation. The six component scores of the NIPS had high internal consistency: Cronbach's alphas were .95, .87, and .88 for before, during, and after the procedures, respectively. Although gestational age and five-minute Apgars were positively associated with NIPS scores over time, there was no association between these factors and responsiveness to pain, as measured by change in NIPS scores from before to during the procedure. Results are discussed in terms of the *use* of the NIPS in clinical trials and its clinical application in a neonatal intensive care unit.

Understanding infant pain was important in providing intervention. This article identified pain scores and infant characteristics and the relationship between the two. Observing infant behavior and identifying infant characteristics of pain was critical to the start of the practicum with continued focus during interventions and throughout the practicum.

Liaw, J.J. (2000). Tactile stimulation and preterm infants. *Journal of Perinatal and Neonatal Nursing, 14,* 84-103.

Abstract: A critical challenge for care providers is improving the outcomes for premature infants. The issues of how to control various kinds of stimulation, provide appropriate sensory stimulation, and maintain the quality of life of premature infants becomes the central focus of care given in neonatal intensive care units. Therefore, intervention research studies that improve the development and quality of life for premature infants are vitally important. This article comparatively analyzes and critiques five intervention studies of premature infants using tactile stimulation and provides future research directions in this area. By examining the effectiveness of the tactile stimulation studies, some evidence and guidance can be provided for researchers generating knowledge in this area as well as nurses involved in clinical care.

Mathai, S., Fernandex, A., Mondkar, J., & Kanbur, W. (2001). Effects of tactile-kinesthetic stimulation in preterms: A controlled trial. *Pediatrics, 28,* 1091-1098.

Abstract: To determine the effects of tactile-kinesthetic stimulation to preterms on physiologic parameters, physical growth and behavioral development, Design: Controlled trial Setting: The premature unit (growing nursery) of a large, teaching hospital. Subjects: 48 well preterms with birth weights between 1000-2000 grams. Intervention: The neonates were systematically allocated into test and control groups. Test babies received tactile-kinesthetic stimulation in the form of a structured baby massage from day 3 to term corrected age. They were observed for changes in vital parameters (heart rate, respiration, temperature and oxygen saturation) during the first few days of stimulation in hospital. Thereafter, massage was continue at home. Changes in weight, length and bead circumference and neuro-behavior (Brazelton Neuro-Behavioral Assessment Scale) were assessed in both groups before, during and after the study period. Results: An increase in heart rate (within physiologic range) was seen in the test group during stimulation. This group also showed a weight gain of 4.24 g/day more than controls, which was statistically significant. On the Brazelton Scale the test group showed statistically significant improved scores on the orientation', range of state', regulation of state' and autonomic stability' clusters at follow-up. No significant complications were noted. A positive correlation was found between the duration of stimulation in days and the weight gain in grams but this did not reach statistical significance. Conclusions: Tactile-kinesthetic stimulation when administered to well, preterm infants has a beneficial effect on growth and behavioral development with no adverse effects on physiologic parameters.

This article identifies that tactile stimulation benefits growth and behavioral development on preterm infants. Tactile stimulation did not have any adverse effects on physiological parameters. This article provides level two evidence.

Modcrin-Talbott, M., Harrison, L., Groer, M., & Younger, M. (2003). The biobehavioral effects of gentle human touch on preterm infants. *Nursing Science Quarterly, 16,* 60-67.

Abstract: This study examined the physiological and behavioral effects of a gentle human touch nursing intervention on medically fragile preterm infants (27 to 32 weeks gestational age). The Roy adaptation model of nursing was the framework for the study. The results of this study suggest that the immediate and short-term effects of a gentle human touch nursing intervention were not aversive or stressful to preterm infants of 27 to 32 weeks gestational age; furthermore, the findings document several positive, beneficial behavioral effects of the intervention on preterm infants and indicate this type of touching may be appropriate for infants in the neonatal intensive care unit.

This occupational therapy intervention was provided throughout the case study's hospitalization. Human touch was soothing for the case study and decreased behavioral distress, decreased motor activity, and promoted state transitioning.

Parker, S., Zahr, L., Cole, J., & Brecht, M. (1992). Outcome after developmental intervention in the neonatal intensive care unit for mothers of preterm infants with low socioeconomic status. *Journal of Pediatrics, 120*, 780-785.

Abstract: The efficacy of developmental intervention in the neonatal intensive care unit for mothers of preterm infants with low socioeconomic status was evaluated. Mothers were assigned to an experimental group in which they met at least weekly with an infant-development specialist or to a control group in which they did not. During the sessions, they participated in a structured developmental and behavioral assessment of their infants, with the goal of enhancing their ability to provide appropriate interactions and environmental stimulation for their infants. When the infants were 4 and 8 months of age, follow-up home visits by a nurse who was unaware of group assignment showed that the experimental-group infants performed more optimally on the Bayley Mental scale (Bayley Scales of Infant Development) at 4 and 8 months of age and on the Bayley Motor scale at 4 months. In addition, the home environment was more developmentally appropriate at 4 months of age, and the mothers rated their babies as temperamentally less difficult at 4 and 8 months. We conclude that a mother-focused, neonatal intensive care unit-based program that utilizes the assessment process in a therapeutic way is an effective strategy in the initiation of interventions for families of low socioeconomic status whose infants were born prematurely.

This study investigates the long term effects of NIDCAP and theories of synactive theory. This article was cited to identify the positive outcomes of NIDCAP in a NICU setting and to support the use of the model with my case study. This study provides level two evidence in which two groups are controlled.

Petryshen, P., Stevens, B., Hawkins, J., & Stewart, M. (1997). Comparing nursing costs for preterm infants while receiving conventional vs. developmental care. *Nursing Economics, 15*, 138-145.

Abstract: The incremental costs incurred by VLBW (less than 1,500 grams) infants during the first year of life accounted for one-third of the $11.4 billion spent in the U.S. on health care. Developmental care for VLBW infants focuses on light and noise management, coordination of interventions to minimize sleep interruptions and positioning/bundling the infant

to prevent disorganization and promote self-regulation. When compared to 60 VLBW infants receiving conventional NICU care, improved physiologic stability measures and fewer days in the NICU were recorded for the 60 VLBW infants cared for by nurses and trained developmental care specialists. Because the move from the NICU to the transitional unit occurred earlier for the developmental group of VLBW infants, and their nursing intensity needs were lower, the average cost savings achieved for this group was $4,340 per infant during the first 35 days of life or less if discharged.

Puckett, B. (2006). Congenital diaphragmatic hernia: Two case studies with atypical presentations. *Neonatal Network, 25*, 239-249.

Abstract: Congenital diaphragmatic hernia (CDH) affects 1 in every 2,000 to 4,000 live births. Many infants with this condition are diagnosed antenatally through routine ultrasound screening. Nearly 90 percent present at delivery with severe respiratory distress requiring intubation. Many of these infants develop persistent pulmonary hypertension of the newborn due to hypoplasia of the affected lung. The survival of infants with CDH is limited by the degree of pulmonary hypoplasia and requires sophisticated medical technology such as high-frequency ventilation and inhaled nitric oxide. Some infants also require treatment with extracoporeal membrane oxygenation. This article gives details of two cases of CDH in which the presentation was atypical. The more subtle presentation is discussed, as well as the embryology and pathophysiology of CDH and the possibility of associated anomalies. Clinical management and impact on the family are outlined.

This article identified two case studies with CDH the diagnosis of my case study. This article assisted in understanding the medical background of an infant with CDH. This article provides level five evidence.

Sweeney, J. & Gutierrez, T. (2002). Musculoskeletal implications of preterm infant positioning in the NICU. Journal *of Perinatal and Neonatal Nursing, 16*, 58-70.

Abstract: Alignment and shaping of the musculoskeletal system occur during each body position that infants experience while in neonatal intensive care. Neonatal nurses and physical therapists can play a major role in designing, modeling, and teaching positioning strategies that promote skeletal integrity, postural control, and sensorimotor organization. Musculoskeletal maturation processes and adverse musculoskeletal consequences are reviewed with an emphasis on clinical implications for neonatal care, discharge teaching, and follow-up. Recommendations are offered for neonatal positioning procedures to prevent extremity malalignment, skull deformities, and gross motor delay.

This article supports the theory that infants, who are medically fragile, are at risk and experience restrictions in mobility and muscle integrity. This article was cited when describing the risks of prolonged immobility and medical fragility of my case study. This article provides level five evidence in which reports expert opinion.

Taquino, L. & Lockrode, T. (1999). Caring for critically ill infants: Strategies to promote physiological stability and improve developmental outcomes. *Critical Care Nurse, 19,* 64-79.

Abstract: Promoting organization and delivering developmentally supportive care leads to improved outcomes for infants and their families. Critical care nurses must function as catalysts to expand the thinking of caregivers from a dimension consisting primarily of physiology to one that embraces the emotional and cognitive growth and well-being of the patient, the patient's family, and staff members. For critically ill infants, developmentally supportive care that is relationship based and that promotes the balance of organized neurobehavioral and physiological function is an avenue to achieve that end. Beneficial or adverse outcomes of nursing care used during this critical period can persist long after an infant is discharged from the intensive care setting.

This article assisted in understanding a critical ill infant and encouraged strategies to promote physiological stability and improve developmental outcomes of critically ill infants.

The Commission on Practice. (2006). Specialized knowledge and skills for occupational therapy practice in the neonatal intensive care unit. *American Journal of Occupational Therapy, 60*, 659-668.

Abstract: The purpose of this paper is to provide a reference for occupational therapists on the advanced knowledge and skills necessary to practice in a neonatal intensive care unit (NICU). Occupational therapy practice with infants in the NICU and their families is high risk and specialized, only appropriate for occupational therapists with advanced knowledge and skills in neonatal care.

This journal article details the special skills and knowledge required to practice occupational therapy in the neonatal intensive care unit. Not many articles are available that detail the specific information that occupational therapists need to know when practicing in the specialized area. This information is important to know in preparing to complete my capstone project in a neonatal intensive care unit. This article provides level five evidence in which reports expert opinion.

Vergara, E. (2002). Enhancing occupational performance in infants in the NICU. *OT Practice, 7(12)*, 8-13.

This article defines typical infant occupations and activities. The author identifies occupational therapy's role in the NICU to support infant's engagement in meaningful occupations through different intervention approaches: create or promote, maintain, modify, prevent, and establish as part of the Occupational Therapy Practice Framework: Domain and Process. This article identifies the need to ensure that occupational therapy practice in a neonatal intensive care unit be centered around our profession's conceptual framework. This framework would enable the profession to focus on interventions that facilitate engagement in occupation to support the infant's participation in life. This article was cited in my case study article.

Vergara, E., & Bigsby, R. (2004). *Developmental and Therapeutic Interventions in the NICU*. Baltimore: Paul H. Brookes.

With a unique developmental and therapeutic perspective, this comprehensive book gives NICU professionals the strong foundation of clinical knowledge they'll need to work with at-risk newborns. Research findings and practical guidelines come together in a single volume clinicians will use to promote the well-being of infants in the NICU and involve and support their families.

This book identifies and defines occupations of infants and caregivers. This was cited in my case study article. Vergara and Bigsby are well-known for their work in the NICU and occupational therapy's role in the NICU.

Westrup, B., Kleberg, A., von Eichwald, K., Stjernqvist, K., & Lagercrantz, H. (2000). A randomized, controlled trial to evaluate the effects of the Newborn Individualized Developmental Care and Assessment Program in a Swedish setting. *Pediatrics, 105,* 66-72.

Abstract: *Background and Objective.* Family-centered developmentally supportive care of very low birth weight infants, provided by the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) has been reported to have positive medical and economic impacts. Our aim was to investigate its effect on need of ventilatory assistance, growth, and hospitalization in a Swedish setting. *Methods.* Preterm infants born between September 1994 and April 1997 with a gestational age <32 weeks and with a need of ventilatory assistance at 24 hours were randomly assigned to either NIDCAP (*n* = 12) or conventional care (*n* = 13). The 2 groups were comparable (median [range]) with respect to birth weight (1083 [630-1411] vs 840[636-1939 g]), head circumference (24.0 [22.3-26.5] vs 24.0 [21.1-30.0 cm]), gestational age (27.6 [24.0-28.7] vs 26.1 [23.9-30.3] weeks), female/male ratio (3/9 vs 9/8) and Clinical Risk Index for Babies (4.0 [0-11] vs 6.0 [2-15]). The infants in the intervention group were cared for in a separate room by a group of specially trained nurses. Formal weekly observations of these infants starting within 3 days after birth and continuing until 36 weeks postconception were used to develop individualized care plans. These plans provided recommendations as to how care might be attuned to the current developmental stage of the infant and how the family might be supported and stimulated to participate in this care. The treatment of the 2 groups was in all other respects identical. *Results.* The duration of mechanical ventilation (median [range] was 2.8 [0-36.7] days in the intervention group vs 4.8 [.1-29.8] days; not significant [NS]) among the controls and continuous positive airway pressure was applied for 26.1 (6.9-52.0) vs 43.9 (5.0-65.1) days. Supplementary oxygen was withdrawn at 33.0 (29.3-35.7) vs 38.1 (33.1-44.9) weeks of postconceptional age (PCA). The weight gain up to 35 weeks of PCA was 13.0 (6.7-21.0) vs 9.8 (6.8-16.6) g/day (NS). The head growth up to 35 weeks of PCA was .73 (.56-1.3) vs .63 (.56-.77) cm/week (NS). The age of the infant at discharge was 38.3 (36.1-57.7) vs 41.0 (36.9-48.4) weeks of PCA (NS). *Conclusions.* NIDCAP does not seem to have detrimental effects on Swedish very low birth weight infants in comparison with conventional care. Indeed, NIDCAP might even be advantageous.

This article was cited in my case study article. This randomized controlled trial study investigated the effectiveness of NIDCAP. Five other randomized controlled trial studies have

supported this study and reported effective use of NIDCAP theories with infants in the NICU. As a randomized controlled trial study, this study provides level one evidence in which the results can be considered credible and generalizable.

White-Traut, R., Nelson, M., Silvestri, J., Cunningham, N., & Patel, M. (1997). Responses of preterm infants to unimodal and multimodal sensory intervention. *Pediatric Nursing, 23*, 169-175.

Abstract: To examine the immediate responses of preterm infants to two forms of unimodal [auditory only (A) and tactile only (T)] and two forms of multimodal sensory stimulation [auditory, tactile and visual (ATV); auditory, tactile, visual and vestibular (ATVV)]. METHOD: A convenience sample of 54 clinically stable preterm infants (33-34 postconceptional weeks) was randomly assigned to 1 of 5 experimental groups [Control (C); (A); (T); (ATV); and (ATVV)]. Stimulation was applied for 15 minutes once daily for 4 consecutive days. RESULTS: Outcome measures included pulse (PR) and respiratory rate (RR), oxygen saturation, behavioral state (BS), and body temperature. Repeated measures ANOVA identified significant differences among the groups during intervention for PR ($p < .001$), RR ($p = .01$), and BS ($p < .02$). Infants receiving any intervention with a tactile component showed increasing arousal (change in BS), and increased PR and RR during stimulation. Group T infants had higher proportions of PR > 180 while Group ATVV had higher proportions of PR < 140 ($p = .0001$). Group ATVV showed increased alertness following stimulation (24%) in contrast to having the least alertness during stimulation (11%). CONCLUSIONS: Tactile stimulation alone may be too arousing for these infants while the addition of vestibular stimulation may modulate arousal and facilitate optimal arousal prior to feeding.